



UPSforDownS

United Parent Support for Down Syndrome
Support • Information • Community

March 2017

In this Issue

Note from the Board	1
At a Glance	2
Marriage & the Family	3-4
Parent Night Out	4
April Meeting.....	4
Miles Count	5
Scholarships	5
Commitment to Excellence	6
Theatre Classes	6
Shamrock Shuffle	6
Social Clubs.....	7
Adult Matters: Employment	8
Lion King Jr.....	8-9
Monochrome>Full Color ...	10
Parent Coffee	10
Family Friday	10
Meet Blake	back page



Lion King featured giraffes.
ON STILTS! More on p. 8!

Note from the Board.

Dear UPS for DownS Families,

When my wife and I found out our baby-on-the-way would be born with an extra chromosome, we really didn't know what to think or where to turn. Jess did tons of research online to prepare our family as best she could for what was to come. We visited other organizations to see what was out there and what was available, but nothing seemed to fit what we were looking for or what we wanted for our family. It was not until we attended our first UPS for DownS Family Friday we knew we had found a home and had the support we were looking for.



Educational Rights

Tuesday, March 21 at 7:30 p.m.
Fox Run Golf Links Clubhouse
333 Plum Grove Road, Elk Grove Village

Charlie Fox, an educational lawyer who concentrates exclusively on special education law and related issues, will explain your child's educational rights, and how to ensure that your child has a free, appropriate public education in the least restrictive environment. Whether your child is not yet three, or well into their educational careers, come and make sure you know what your child is entitled to under the law.

Get details and register for FREE:

www.ufdEducationRights.eventbrite.com

At a glance...

Friday, March 3, 2017
Parent Coffee & Playgroup

Tuesday, March 7, 2017
Adult Matters: Employment

Sunday, March 11, 2017
Junior Teen Social Club

Friday, March 17, 2017
Family Friday

Saturday, March 18, 2017
Parent Night Out
Senior Teen Social Club

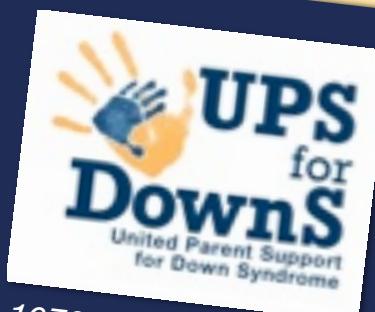
Tuesday, March 21, 2017
Educational Rights

Saturday, March 25, 2017
Adult Social Club

March 31-April 2, 2017
Shamrock Shuffle Expo/Race

Tuesday, April 11, 2017
Parent Coffee & Playgroup
UPS for DownS Town Hall Meeting
Theatre Classes begin

Tuesday, April 18, 2017
College & Down syndrome



1070 S. Roselle Road
Schaumburg, IL 60193
www.upsfordowns.org
847-895-2100

That time seems like so long ago at this point, but it was only a short two and half years ago. Since then, Jess and I have taken over running the Family Fridays and have greatly enjoyed hosting this event for young families, giving everyone a forum to discuss the issues and concerns we all had to face in the early years. In addition to finding us at Family Fridays, Sadie, our oldest, wouldn't dare let us miss a swim party or the holiday party which are always a blast. This year we got to experience our first UFD musical, The Lion King Jr. The entire family loved it. If you happened to be at the Saturday night performance, Penny would be the one cheering when the rest of the crowd was quiet, getting a few giggles from those around us.



When asked to join the board in December of 2015, I excitedly jumped on the opportunity to serve an organization that has already meant so much to our family. I strive to carry on the mission of this great organization and the values our family shares with it.

If you see Jess, Sadie, Penny, and I out at Family Friday or another one of our great programs, please don't hesitate to say hi! I especially hope to see you at the upcoming Town Hall Meeting to learn what is important to you and to brainstorm ideas about how together, we can make a difference for all families!

Warm Regards,

Ryan Rathman

MARRIAGE & THE FAMILY

On February 21, Dr. Dave Niekamp presented "Marriage & the Family: Commitment, Collaboration, and Creation". It may seem surprising, but if one were to Google the average length of a marriage in the United States, most sources state first marriages last between 5-8 years. Dr. Niekamp is a psychologist who specializes in relationship issues, and although the statistics for experiencing a long lasting marriage may seem dismal, he offered advice to enhance the relationship with your spouse by recognizing and removing barriers that might interfere with establishing a solid relationship.

In order to create relationships for longevity, there needs to be conscious deliberation in placing value on the relationship, not the person. This may seem contradictory, but the energy and the commitment needs to be directed to the relationship, not the person. Directing the energies toward the spouse can actually lead to the creation of feelings of resentment or isolation, as energy is spent trying to please one person, consuming the other. If you add children to the marriage, you add further opportunities for isolation and resentment, as attention then shifts to the children. What Dr. Niekamp would like to remind us is that we must be deliberate in choosing the marriage relationship, engaging each other as collaborators, listening to each other. You need to be able to say 'My spouse comes first.' Yes, you love your kids, and you still get together with your friends, but this is your anchor relationship. If you establish this now, it will be easier to hold on to

when life becomes more complicated later.

The development of the marriage relationship can be compared to the creation of diamond. Dr. Niekamp used this analogy, since the diamond ring is the symbol of the marriage promise. Diamonds are made from "scraps of carbon", placed under intense heat and pressure. When we start married life, things may seem wondrous and perfect, and as time goes on, things can change, quickly. There are the conflicts that arise and feelings are hurt, tempers run hot--the heat. Responsibilities increase--kids, job changes, financial worries, etc.--the pressure. If you have placed the value on the marriage relationship, focusing on the two of you, then the relationship will be solid and will be able to sustain the conflicts and pressure and emerge as "hard" as a diamond. Another characteristic of a diamond which equates to a good marriage relationship is clarity. Clarity in a diamond refers to transparency. Clarity in a relationship refers to clear communication, an essential element to successful relationships.

Deliberate efforts need to be made to collaborate with each other. Each spouse contributes in complementary ways, each has his or her own strengths. Concentrated efforts must be made to value and see the contributions of the spouse. Appreciate each other, but do not view each other as a best friend. Remember that your spouse is his or her own person. Remember,



 though you share some experiences, neither of you can completely identify with the other. For instance, although both of you were invested in the creation of children and being present at the births, the husband will never experience childbirth. This is not to say that a husband can not be invested in raising the children, but it speaks to the point that each person brings to the relationship his or her strengths, which allows for different contributions that complement each other.

To create a healthy marriage, it is helpful to compare the relationship to a painting. Painting requires getting messy, and creating a solid marriage can be messy. There will be times when things are not "rosy", but if you have taken the time to invest in deliberately making time for each other and listening to each other, then the messiness of life will not prevent you from keeping your eye on the end product, the painting, your relationship. Too often, as things get difficult, it is easy to become passively tolerant, leading to apathy, resentment or hostility toward a spouse. Life is busy, but it is necessary for both parties to make specific and deliberate efforts to learn from and listen to each other. This can be as simple as dedicating 15 minutes a day to talk to each other, expressing feelings, rather than talking at each other, reporting on the events of the day. This is the time to "lean in and move closer", since together is better, as Dr. Niekamp suggests. The last piece of advice that Dr. Niekamp gave was to keep in mind that you are not striving for perfection, for no one is perfect. You are attempting to do the right things, even if done poorly, rather than continue doing the wrong things efficiently. Focus on learning from each other, listening to each other, and applying deliberate effort in commitment, collaboration and creation of your marriage relationship.



PARENT NIGHT OUT

Date: Saturday, March 18
Time: 7:00 p.m.
Where: Reza's Restaurant
40 N. Tower Road, Oak Brook, Illinois
Cost: \$20 per person
UPS for DownS covers the balance

RSVP to
sneri@upsfordowns.org
Limit 24 guests

APRIL MEETING: COLLEGE & DOWN SYNDROME

Tuesday, April 18th • 7:30 p.m.

Fox Run Golf Links Clubhouse, 333 Plum Grove Road; Elk Grove Village
Many local colleges and universities are working to make college an option for all students, including students with Down syndrome. Come learn from program representatives about the growing possibilities for postsecondary education in our area!

RSVP and get more information at: <http://ufdCOLLEGE.eventbrite.com>



MILES COUNT. CHROMOSOMES DON'T. Do the distance for Down syndrome.

Bank of America Chicago Marathon

Rock 'n' Roll Chicago Half Marathon & 10K

Bank of America Shamrock Shuffle 8K

The Super Run Chicago 5K

marathon@upsfordowns.org

UPS FOR DownS RUNS CHICAGO

UPS for DownS Sibling Scholarship

- One \$2500 scholarship to an individual who is pursuing a post secondary degree and is a sibling of a person with Down syndrome

DOWNLOAD APPLICATION AT
www.upsfordowns.org

IMPORTANT DATES:

Deadline to apply: April 1, 2017
Winners announced before May 1.

ANY QUESTIONS, CONTACT:
scholarship@upsfordowns.org

Katie MacDonald Memorial Scholarships

- Two \$2500 scholarships to individuals with Down syndrome who are pursuing educational or job training opportunities
- Two \$2500 scholarships to individuals pursuing a post-secondary degree in a disability related field



APPLICATIONS MUST BE SUBMITTED BY APRIL 1, 2017

UPS for DownS
1070 S. Roselle Road
Schaumburg, IL 60193
847.891.2100

COMMITMENT TO

EXCELLENCE

UPS for DownS formally recognizes the people or organizations that enrich the lives of people with Down syndrome through its "Commitment to Excellence" Award. The CTE is for recognition of those who have helped people with Down syndrome, their families and/or this organization.

NOMINATE
SOMEONE
TODAY

Nominate your educators, medical professionals, organizations, coaches, volunteer or others. Nominations are due by April 15th and must be in writing. **All information must be provided at time of nomination to be considered.**

**Nominations may be made online at
CTEnomination.eventbrite.com**

UPS FOR DownS SHAMROCKS CHICAGO We need you!

Volunteer for us at the Shamrock Shuffle Race Expo at McCormick Place!

**Friday, March 31 - 10 a.m. to 8 p.m.
Saturday, April 1 - 9 a.m. to 6 p.m.**

No running experience necessary, we'll have experts on hand to answer those questions. You just bring enthusiasm and willingness to smile and talk to people.

www.ssvolunteers.eventbrite.com

THEATRE CLASSES

**ALL CLASSES TAKE PLACE ON
Tuesday evenings beginning April 4**

5:00 - 6:00 p.m. A STAR IS BORN.

This exciting performance based class is meant to introduce new actors to the stage. **Ages 5 - 12, but meant for folks new to musical theatre. 4 minimum/12 maximum. April 4 - May 9 (6 weeks) \$60**

5:00 - 6:00 p.m. THE ABC'S OF

AUDITIONS. This is the perfect class to learn how to knock an audition out of the park! **Ages 10 to adult. 4 minimum/12 maximum. April 4 - May 16 (7 weeks) \$75**

6:15 - 7:15 p.m. DECISIONS TO

ACTIONS. This non-performance class will explore situations that take some real life maneuvering, including asking someone on a date, what to do when you're really angry, how to use social media, and more. **Ages 10 to adult. 4 minimum/12 maximum. April 4 - May 16 (7 weeks) \$75**

7:30 - 9:00 p.m. ROMEO AND JULIET. Join the

star crossed lovers and their families bloody feud in a 90 minute cutting of the most romantic story of all time! This play inspired countless others, like West Side Story and High School Musical! Costumes, sound design, everything. **Ages 10 to adult. 4 minimum/16 maximum. April 4 - May 30, plus performance dates (9 weeks) \$100**

ALL CLASSES held at Conant High School, 700 E. Cougar Trail, Hoffman Estates.

JUNIOR TEEN SOCIAL CLUB

AGES 13-16
intended for
**JUNIOR HIGH &
MIDDLE SCHOOL**

WHEN: Saturday, March 11, 2017
TIME: 2:15 p.m. SHOW STARTS AT 2:30 P.M.
WHAT: Theatre outing: Lion King, Jr.
WHERE: Prairie Lakes Theatre, 515 E. Thacker, Des Plaines
COST: FREE for participant. SPACE IS LIMITED.
Tickets must be purchased in advance, so RSVP ASAP!
RSVP: www.JRteensMarch2017.eventbrite.com
Questions: Contact Heather at hvargas@upsfordowns.org or 630-667-6920
Family may purchase tickets at the door or in advance, if available.

SENIOR TEEN SOCIAL CLUB

AGES 14-21
intended for
**HIGH SCHOOL
TRANSITION**

WHEN: Sunday, March 19, 2017
TIME: 2:15 p.m. SHOW STARTS AT 2:30 P.M.
WHAT: Movie Premiere Weekend: BEAUTY & THE BEAST
WHERE: Century Theaters at Deer Park Town Center
21600 Field Parkway, Deer Park, Illinois
COST: \$5 per participant (includes movie, popcorn, soft drink and arcade tokens!)
Tickets must be purchased in advance. **RSVP by MARCH 12.**
www.seniorteensscene-beautyandthebeast.eventbrite.com
Questions: Contact SeniorTeens@upsfordowns.org

ADULT SOCIAL CLUB

AGES 21 & UP

WHAT: Pinstripes Bocce and Bowling
WHERE: Pinstripes Oakbrook, 7 Oak Brook Center
WHEN: Saturday, March 25, 2017
TIME: Meet at 7:00 p.m. - 10:00 p.m.
COST: \$10 per person
RSVP: <http://ASCpinstripes.eventbrite.com>
All friends, siblings and colleagues age 21 and over, with or without Down syndrome are invited and encouraged to attend. **No parents, please.**

ADULT MATTERS: EMPLOYMENT SERIES

Tuesday, March 7, 2017

7:00 - 9:00 p.m.

Fox Run Golf Links, 333 Plum Grove
Road, Elk Grove Village

Department of Rehabilitation Services is dedicated to helping people with disabilities achieve employment goals. The vocational rehabilitation program helps people get real jobs for real pay in the community.

Doug Morton, manager of the DRS Strategic Management Unit, will help families get a global perspective of how DRS services and supports work, the actual nuts and bolts of the process, personnel and services.

Sign up and get more information:
www.EmploymentSeries.eventbrite.com





10 YEARS OF AWESOMENESS

On February 2 - 5, 2017, UPS for DownS Theatre Company celebrated a TEN YEAR anniversary in partnership with EDGE Productions with four sold out performances of the iconic Lion King Jr, at Schaumburg Prairie Center for the Arts!

This show was the most ambitious musical to date put on by this incredible cast, featuring over sixty cast members fully costumed, staged in the African savanna complete with giraffes on stilts, elephants, rhinos, Pride Rock, lionesses, hyenas, wildebeest stampede, Mufasa, Rafiki dancing and singing in African splendor, accompanied by live African drummers!

We thank our fearless leader, EDGE founder, and director Orion Couling and the entire EDGE production team. You push the boundaries of theater, community, and social change. You share our vision and demand our very best, inspiring us all to be better. We are honored to be partners in this vision and to have shared this journey for the past ten years!

This amazing production was double cast. Go to the following links and use the password "Orion" to view hundreds more images:

Thursday/Saturday: <http://tinyurl.com/UFDLKA>

Friday/Sunday: <http://tinyurl.com/UFDLKB>



Our deepest gratitude goes to Sam Duray for rehearsal and cast photos, and to Jennifer Frankfurter at photographywithheart.com for show photos of both casts.

FROM MONOCHROME TO FULL COLOR

By Gabrysia Sniadowski



Throughout my adolescence, I was cautioned that curiosity killed the cat. In my case, it was curiosity that instead saved me. Being raised in a primarily white middle-class neighborhood brought **socioeconomic comfort freckled with ignorance.** **Residents who fell into society's "marginalized" category were few and far between.** Having little exposure to people with disabilities, I felt uncomfortable in their presence. I was unsure of how to establish communication, if at all possible. I elected to stay within my comfort zone, within the parameters of my monochromatic community. This carried me through life comfortably until one day in my freshman year of high school, when the ground shook and opened up before me.

A nonprofit group needed a venue to perform their musical. My school offered to host their performance, and tech crew needed volunteers. I decided to try my hand at tech--perhaps learn something new--and was assigned the spotlight, where all that was asked of me was to point the spotlight at the right person at the right time. I was happy to get experience and hide in the light booth. At least, this was my plan until I met the cast.



FAMILY FRIDAY

is for families of children with Down syndrome from birth to 8 years old (and siblings of all ages). Please join us on

Friday, March 17, 2017

at 6:30 at

KIDTOWN USA
1071 S. Roselle Rd. Schaumburg, IL

RSVP at

www.familyfriday.eventbrite.com

PARENT COFFEE & PLAYGROUP

ALL AGES WELCOME!

NOON - 1:30 p.m.

Tuesday, April 11

First United Methodist Church
1903 E. Euclid Avenue, Arlington Heights

Light lunch & child care provided.

Questions? Contact Shannon at
847-894-8782 or skersemeier@gmail.com



This nonprofit group's members consisted of many youth with Down syndrome. I learned this too late, as I was standing in the middle of the main entrance when the cast first entered. I turned to begin my hasty walk back to the light booth. Before I could take two steps, however, I was being used as a tree branch for a girl with braces to hang onto. Grinning, she introduced herself as Eve and was promptly pried from me by her friend, Sam. Sam apologized and assured me it wouldn't happen again. I found myself telling her that I didn't mind. Later, I realized that I was telling the truth. Just two minutes out of my comfort zone had already affected me. As the week progressed, I met more and more people, each with unique aspects to their disabilities.

At the final matinee, the director invited me to join them for the upcoming year as a part of their performance. "No way," I thought. I was eager to return to my comfortable life. But I soon realized that my comfort zone was no longer of any use to me, that although a comfort zone is a beautiful place, nothing ever grows there. ***If I had any hope of being a compassionate individual, I had to stop making excuses that kept me ignorant.***

I found myself saying yes. Saying yes was the hardest thing I've had to do in a long time. Here I was, some ignorant, new person forced to adopt a new system of patience and understanding beyond that which I already knew.

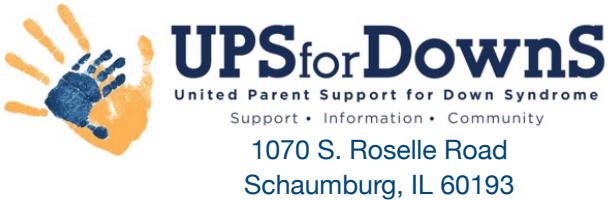


The shows came and went, but the lessons I learned persist. Spending two years with 70 kids whom I would never have gotten to know before shifted my values. I realized that "***disabled***" is a term that leans unfavorably to those it attempts to define. A person is not disabled, but different. The majority of people having a certain ability that another does not isn't definitive of their character or of their

worth. I challenged my understanding of intelligence, and stopped defining it through academic success.

I have become a leader, and understood that a leader does not discriminate. Having learned this, I no longer live my life in monochrome, instead opting for a dash of color where there used to be none. I have learned that ***success is never borne of expectation; it is borne of fearless giving.*** Presented with the situation again, I can only hope that my heart would follow that same curiosity; for there is no greater love than love that is shared.

Gabrysia is a senior at St. Viator High School in Arlington Heights, Illinois. While she has a deep love of theatre and vocal talent, too, she will begin pursuing her medical degree at Tulane University in New Orleans in the fall.



1070 S. Roselle Road
Schaumburg, IL 60193

For changes or additions to our distribution list:
MailingList@upsfordowns.org or 847-895-2100



TUESDAY, APRIL 4 TOWN HALL MEETING

We need to hear from you! See insert.

www.UFDtownhall.eventbrite.com

DATE OF BIRTH: July 18, 2013

OCCUPATION: Preschool Student of the Year and Certified Member of Sesame Street

LAST BOOK READ: Elmo's Potty Time

FAVORITE THING ABOUT SCHOOL: Painting Art Masterpieces

HOBBY: Drawing and being creative

FAVORITE FOOD: Pizza

FAVORITE MOVIE(S):

Ice Age; Alvin & the Chipmunks

LATEST ACCOMPLISHMENT:

Walking upright up and down the stairs, by myself!

QUOTE: "Why fit in when you were born to stand out!" ~Dr. Seuss

JOKE: What is a pirate's favorite letter?

"R"!!!

BLAKE MATTHEW
Nickname: Bebo Buttons

